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# The Use of Medication for Challenging Behaviors in People with Intellectual Disabilities: The Direct Care Providers' Perspective

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## ABSTRACT

**Background:** Overmedication of people with intellectual disabilities, particularly when psychotropic medications are used for challenging behavior (CB) in the absence of a psychiatric disorder, is a significant public health concern. Support staff play a pivotal role in influencing the prescribing process. Staff views and attitudes toward medication use for CB are therefore of paramount importance.

**Method:** We have conducted four focus groups involving support staff ( $n = 8$ ), home managers ( $n = 5$ ) and trainers ( $n = 3$ ), two of which primarily explored participants' experiences and views on using medication for CB and medication withdrawal.

**Results:** Some participants felt medication use was justified, but others saw that as a form of chemical restraint. Most agreed that polypharmacy of psychotropics might lead to side effects. Some acknowledged the lack of shared decision-making involving people with intellectual disabilities and their families. There was universal anxiety about withdrawing the medication.

**Conclusions:** All agreed on the need for more medication-related information.


## KEYWORDS

People with intellectual disabilities; challenging behaviors; the use of psychotropics; support staff's views; service managers' views; trainers' views

## Introduction

Overmedication of people with intellectual disabilities, particularly the off-license use of psychotropic medications for challenging behaviors (CB) in the absence of a psychiatric disorder, is a major public health concern (Glover et al., 2015). As a result, in 2016, NHS England in the UK launched a major initiative called STOMP (STopping Over-Medication of People with learning disabilities, autism or both) (Branford et al., 2019). Three decades ago, Deb and Fraser (1994) highlighted that half of the adults with intellectual disabilities received psychotropic medication even after discharge from hospitals to

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community settings. This rate remains similar even today as Sheehan et al., more recently (Sheehan et al., 2015) found that 49–63% of adults with intellectual disabilities in the UK receive psychotropic medication. This is despite the national (National Institute for Health and Care Excellence (2015); Unwin & Deb, 2010; [ld-medication.bham.ac.uk](http://ld-medication.bham.ac.uk)) and international guidelines (Deb et al., 2009) recommending the use of non-pharmacological psychosocial/behavioral interventions such as the implementation of a behavior support plan (BSP) based on positive behavior support (PBS) (Gore et al., 2022), cognitive behavior therapy (Nicoll et al., 2013), anger management (Willner et al., 2013), mindfulness-based meditation (Shogren & Singh, 2022) etc. for CB first before psychotropic medications could be considered. CB, like verbal aggression, physical aggression toward others, property and self (self-injurious behavior), may be displayed by up to 60% of adults with intellectual disabilities (Deb, Unwin, et al., 2022). CB could be difficult to manage, cause distress to people with intellectual disabilities, their families and people around them, and may lead to restrictive practices and loss of community placements leading to hospitalization and may limit access to community facilities (Deb et al., 2016). The causes of CB are multifactorial (Jones et al., 2008), including physical (pain), psychological (depression, psychological trauma, stress) and social/environmental (inappropriate environment), which require a multi-disciplinary and multi-agency approach to assessment and intervention (Hemmings et al., 2013).

Long-term use of psychotropics carries the risk of side effects (Deb, 2016) and affects the person's quality of life (QoL) (Ramerman et al., 2018). Withdrawal of psychotropics, particularly antipsychotics, on the other hand, is possible in a high proportion of adults with intellectual disabilities leading to improvement in side effects and QoL (Deb et al., 2023; Deb, Bertelli, et al., 2022; de Kuijper et al., 2014; de Kuijper & Hoekstra, 2018; Shankar et al., 2019; Sheehan & Hassiotis, 2017; Deb et al., 2023). Moreover, studies, including ours, have shown that some adults with intellectual disabilities were dissatisfied with medication, mainly due to lack of involvement in the treatment decision, adverse effects, lack of efficacy and a “desire to lead a normal life” (Hall & Deb, 2008; Hassiotis et al., 2016; Sheehan et al., 2018; de Kuijper et al., 2022). Recent studies showed that family caregivers felt there should be a holistic approach to behavior management rather than an over reliance on medication alone (Hassiotis et al., 2016; Sheehan et al., 2018).

Support (direct care) staff play a pivotal role in influencing the prescribing process by asking prescribers in the first place to prescribe medication for CB and given the lack of evidence of effectiveness, are overly optimistic about the medication's potential efficacy (Christian et al., 1999; de Kuijper & van der Putten, 2017). Support staff also are most anxious and often obstructive to the prescriber's attempts to withdraw psychotropic medication when appropriate (Sheehan et al., 2018). Previous surveys of support staff in Australia (Donley et

al., 2012) and the Netherlands (Kleijwegt et al., 2019) showed most staff felt the use of psychotropic medications for CB is appropriate. Ahmed et al. (2000) during a randomized antipsychotic withdrawal trial found poor staff training hampered the success of the withdrawal process (Deb, Bertelli, et al., 2022). Proper training and support for support staff are thus of paramount importance for a successful program of rationalization of psychotropic medication use in adults with intellectual disabilities. In a recent study on staff attitude, we found that most participants were familiar with the concept of PBS, which could be used without relying on medication to support people with intellectual disabilities who display CB (Deb, Limbu, et al., 2022). Therefore, it is crucial to assess staff perception and views about medication use for CB before these issues can be addressed through proper staff training.

In our previous study investigating how caregivers perceive “triggers for CB,” only a few care staff explicitly reflected that their own behavior might influence aggressive behavior (Unwin, 2014; Limbu et al., 2021). Furthermore, only 16% of staff mentioned issues around communication despite much aggressive behavior being considered communicative (Matson et al., 2012). Staff felt they would benefit from training and information about potential triggers to help them think more about environmental factors and their own role in precipitating CB. Many other researchers have highlighted support staff’s frustration for not having the proper training and desire to gather more knowledge and training on (a) mental health issues, (b) medication prescribing-when to use them and why, and when not to use them and why, (c) medication side effects, (d) and when and how medication could be safely withdrawn (Lalor & Poulson, 2013).

We have addressed the staff training issues mentioned above by co-producing online training resources delivered through face-to-face interactive workshops for support staff and caregivers caring for adults with intellectual disabilities in community settings. The training program is called SPECTROM (Short-term Psycho-Education for Carers To Reduce OverMedication of people with intellectual disabilities), which was developed to upskill staff on psychotropic knowledge and change attitudes toward CB and the person manifesting CB to encourage alternatives to medication to address CB (<https://spectrom.wixsite.com/project>) (Deb, Limbu, et al., 2020). Two small pre, and post-intervention pilot studies of SPECTROM training in the UK (Deb et al., 2021) and Australia (Barratt et al., 2023; Wilson et al., 2023) have received good feedback from the trainees and the trainers on the acceptability, practicality, applicability and relevance of SPECTROM to their practice and helped to empower support staff by increasing their knowledge of psychotropic medication and improving attitude toward using medication for challenging behavior.

To inform the contents of SPECTROM resources, we have conducted four focus groups involving support staff, house (service) managers and PBS

trainers. Although there was some overlap, two focus groups primarily explored experiences and views on using psychotropic medications for CB in adults with intellectual disabilities and the potential for their withdrawal when appropriate, and the other two discussed possible contents for SPECTROM. In this paper, we have presented findings from primarily two focus groups that concentrated on staff views on the psychotropic use for CB and described in the Discussion section how these findings have helped to develop the contents of SPECTROM resources.

## **Materials and methods**

### ***Study Sample***

We conducted four focus groups: two with support staff only and two with service managers and PBS trainers. Although there was some overlap among these four focus groups, we have presented data in this paper primarily on two focus groups that explored the views of the support staff (one focus group), and the service managers and the PBS trainers (one focus group) on the medication use for CB. We defined those eligible to participate in the study as paid caregivers, managers, and trainers who worked with adults with intellectual disabilities who showed CB. Participants meeting these criteria were purposively sampled for each group to ensure that different organizations were represented. Participants had a range of experiences regarding how long they worked with people with intellectual disabilities. Although we did not collect data on the exact years of working experience in this field, we asked the service managers to choose support staff with varied lengths of work experience in caring for people with intellectual disabilities in community homes. This was a qualitative study, so no formal sample size calculation was required. However, we aimed for an optimal focus group size of 6–8 participants in each group to promote dialogue, group coherence and group management.

To recruit participants, a research advertisement was sent through the UK Voluntary Organizations Disability Group (VODG), an umbrella organization of more than 35 social care service providers in the UK (social service, voluntary and independent sectors). Nine large service provider organizations expressed interest in participating, of whom eight finally agreed to participate. These are Mencap, Challenging Behavior Foundation (CBF), Achieve together, AT-Autism, Avenues Group, Dimensions-UK, Milestones Trust, and National Autistic Society. Each organization identified one available house manager and trainer for the focus groups, and each house manager identified two support staff.

We invited nine support staff, and eight ultimately participated (six females). Five service/house managers (all females) and three trainers (one

female) were invited, and all participated in the focus groups. The two focus groups (service managers and PBS trainers; and support staff) were separated to avoid influence of managers on staff members. There were four support staff from Dimensions, one from Mencap, two from Milestone Trust and one from Achieve Together. There was one manager from Achieve Together, two managers from Dimensions, one manager from Mencap, one trainer from Achieve Together. There was one trainer from Milestones Trust, one trainer from Dimensions and one trainer from Avenues Group. However, support staff or managers from the same service providers worked in different community homes.

### ***Conduct of Focus Groups***

The focus group discussion was based on a topic guide (see supplementary material 1), which reflected themes that mapped to the project's a priori aims and objectives and was further informed by findings from the literature review. After discussion with the core team (SD, BL and GU) and other relevant stakeholders, the topic guide was finalized. The topic guide was employed flexibly during the focus groups, and while the researcher remained open to emergent themes, these were framed using the Theory of Planned Behavior (Ajzen, 1991). In this way, we examined beliefs and attitudes (e.g., about psychotropic medication and alternative approaches such as PBS) and how these might influence behavior (e.g., requesting support from professionals to prescribe medication or providing help with alternative approaches).

A researcher (BL) with previous experience in conducting qualitative research ran the focus groups with co-facilitation from the chief investigator (SD) and supervision from an expert in qualitative research (TW). We have used this approach in previous studies where we interviewed caregivers of people with intellectual disabilities and head injuries (Deb et al., 2007; Deb, Aimola, et al., 2020; Morris et al., 2005). Eligible participants were then sent a study summary and an information sheet. Once participants agreed, written informed consent was taken. The focus groups were held face-to-face at a venue in London, the UK, in April 2019. Each focus group lasted for approximately 90 minutes. The two focus groups data presented here explored issues around participants' perceptions and views on medication use for CB and the potential for withdrawal of these medications where appropriate.

### ***Data Management and Analysis***

The focus groups were audio-recorded using pseudonyms and professionally transcribed. Transcripts were uploaded to NVivo 12 plus for windows software to store and manage the data and support analysis.

The data were analyzed using thematic analysis (Braun & Clarke, 2006). Initially, the transcripts were read to ensure immersion and familiarity with the data before formal coding was undertaken. After that, an initial coding frame was developed by allocating a unique code to themes progressively organized in a framework comprising primary and secondary sub-themes. The coding frame was developed and continuously reviewed and refined as new codes emerged. Two authors (BL and SD) independently analyzed data to achieve a consensus. This development of the coding framework and the analysis was also overseen and verified by an experienced qualitative researcher (TW).

The data and supporting quotes were indexed using the agreed coding framework. Similar codes were categorized together to produce patterns and themes. The identified categories were also reviewed to ensure the emerging category was a discrete category and modified as necessary. Ultimately the coding framework was employed to search the data for patterns and emerging themes. The identified themes were then reviewed and revised if needed. Once no new themes emerged, the themes were finalized and defined.

## Results

The results section presents the main themes and subthemes followed by relevant quotes directly from the transcripts. Two main themes were (a) medication and (b) the withdrawal of medication. Within each of them there were several subthemes. We have used codes in the parenthesis such as “SS” for support staff, “SM” for service/house manager, and “TR” for the trainer to identify the quotes from the different groups of participants.

## Medication

### ***Concern About the High Dose and Polypharmacy***

Participants could identify people with intellectual disabilities they had worked with who were prescribed medication at high doses or

*... . . . he was taking, uh, like 150% over what he was supposed to be taking daily. (SM)*

multiple medications, including sometimes additional medication used to counteract the side effects of other medication and expressed their concerns about the side effects this may cause from drug-drug interactions.

*... . . . he was on a high dosage of medication, and with that, I guess my concern is the combination of medication . . . . as well as the side effects each one of those medications may have. Sometimes medication is given to counteract the other side effects that one medication gives. So, it's almost like a chain reaction when taking medication. (SS)*



They also identified how polypharmacy could produce side effects through drug-drug interaction.

*We had someone that was prescribed medication and, actually it was interacting and made that person really unwell. . . . . that there was this side effect and phoned the GP . . . . . and immediately the medication was stopped. (SM)*

### **Need for Staff Awareness/training**

The group commented that a lack of staff awareness and knowledge about psychotropic medication often leads to overmedication.

*I think in the past all my experience of working in learning disability sector has been some of, um, the service users have been overmedicated due to the awareness issues. (SM)*

### **Physical Problem Causing Challenging Behavior**

Some participants recognized that an underlying physical problem might lead to CB, which was then treated wrongly with psychotropic medication.

*I know for a fact people have been given anti-psychotic medication and actually it's something physical that's wrong. (SM)*

### **The Need for a Clear Guide for the Use of (PRN) as Required Medication**

As required, "PRN" medication was identified as potentially being open to abuse as support staff may use it too frequently to manage CB.

*...then after a few months, I found out that my colleagues would give the person this PRN when he was becoming over-challenging. So, it's an abuse of this PRN thing." (SS)*

The participants, therefore, wanted detailed, clear guidance around "as required" medication to ensure its appropriate use.

*...when is it right to administer PRN if it is based around CB? Because we all have different perceptions of what it might be. So that needs to be clear on that guidelines to when should it be used. (SS)*

### **Medication Side Effects and Their Impact on Quality of Life**

The participants discussed various side effects of psychotropic medications such as Parkinsonism, weight gain and drowsiness.

*...that brought on side effects such as Parkinson's . . . .so causing really bad problems with mobility. (SS)*

*But she's got a massive increase in weight gain and obviously that comes with its own side effects . . . . (SS)*

They were concerned about the impact these side effects have on people they support, affecting their quality of life.

*. . . he is tired and that's because of the medication so he's not able to participate in things that he generally would want to do. (SS)*

### ***Need for Regular Medication Reviews***

This led to a discussion on the need for regular medication reviews and a full assessment of CB before using medication. Participants emphasized the need for a robust person-centered care plan to avoid overmedication, and they endorsed the rationalization of medication prescription where necessary by reducing the dose or discontinuing the medication.

*So, we are saying does this person need to be on the medication, um, can it be reduced? So, we are looking at those areas, each person on those types of medication had a strong action plan as well and we review that on a regular basis, you know. Does it still need to continue; can we reduce it? (SM)*

*There has to be a review. How often the review is, and I guess also the data that is also presented in the review to make a concise judgement on what happens next. (SS)*

### ***The Importance of Shared Decision Making Involving the Person and Their Families***

Participants also raised the issue of lack of shared decision making which may raise an ethical question.

*But nobody asked them (people with intellectual disabilities) if they are happy or not. (SS)*

### ***Possible Negative Impact of the UK STOMP Initiative on Psychotropic Prescribing***

Participants discussed the impact of the UK STOMP initiative on the people they support. Some expressed anxiety regarding the withdrawal of medication without a proper contingency plan.

*. . . . this could have backfired the other way that when somebody has a genuine psychiatric illness, perhaps needs some medication because of the STOMP, the prescribers are a bit worried about prescribing anything. (SS)*

Some expressed concern that even some community learning disability team members may now be reluctant to see psychotropic medication use because of the UK STOMP initiative, even if there is an underlying psychiatric illness.

*... . . . discuss with the psychiatrist and perhaps we should try some sort of antidepressant. And then we received from the community team a message that that mm, not nice to play with antidepressant. (SS)*

### **Difference in Staff Attitude Toward Medication Use for Challenging Behavior**

The participants discussed the crucial issue of their own attitude toward medication use to address CB, which exposed some conflicting views. Some felt that sometimes medication could improve the person's QoL and, therefore, justified.

*I would prefer not to be on medication. That's me. But if, with the medication it's going to help them to have a quality life then, I, I think they should. (SS)*

Others felt medication use was inappropriate most of the time as it could be perceived as an attempt to sedate the person or as a form of chemical restraint.

*What is it, mood stabiliser? It's another word for sedation, isn't it? So, but they are called beautifully mood stabiliser. (SS)*

*"Because medication, these antipsychotics are basically another form of restraint." (SS)*

### **The Need for a Balanced Approach to Prescribing by Weighing Up Benefit Vs Harm**

They felt a balanced approach between the good and bad effects of medication should be taken. There was consensus that there should be a clear rationale for using medication.

*So, it's trying to weigh up those difficulties with the side effects for him, um, having a better quality of life but struggling more with mobility. (SS)*

### **Medication withdrawal**

As support staff and families have much anxiety about withdrawing psychotropic medication, which may precipitate anxiety in the person with intellectual disabilities leading to distressed behavior upon withdrawal, participants had further discussion on this critical topic.

### **Negative Experience Due to Withdrawal Side Effects**

Whilst the participants shared stories of successful withdrawal from antipsychotics, they described the process as challenging and were concerned about potential side effects.

*So taking them off the medication can sometimes be worse, um, than leaving them on the medication, especially if you haven't got anything else in place to help support the person with their behaviours or support staff. (SM)*

### **Negative Experiences of Medication Withdrawal Due to Lack of Support**

Most staff expressed concern regarding the lack of support during the withdrawal process. The participants highlighted a lack of information about what might happen and how best to help the person as they encounter withdrawal side effects.

*... because we didn't really have any support or any, um, kind of information on what was going to happen when that lady withdrew from the medication. (SM)*

*... we have tried to withdraw someone from a medication but there were issues of that in that there wasn't really any support for us in how to help the person withdraw properly ... (SM)*

### **Positive Experience of Medication Withdrawal**

However, one staff member said that her organization has a good support structure to support the withdrawal process.

*We always make sure when we've done reduction that we've got staff in place. Like maybe one to one support hours, person sits with them or you know we've got someone come in his room for therapy. So many different things. (SS)*

### **Medication Withdrawal Helping to Move Out of Institution to More Independent Life Due to Improved Quality of Life as a Consequence of Improvement in Medication Side Effects**

Encouragingly staff and service managers shared stories of people they support who successfully came off psychotropics after long-term use, leading to an improved QoL because of a reduction in medication side effects.

*... the first reduction was successful. He was much more lucid, much more um, he was articulating a lot more with us. He was going out in community a lot more. He was um, engaging with a lot more activities that he wasn't doing before. ... another lady who was on risperidone for years, she was on it since I started working there and she's now been taken completely off. And she's lost a massive amount of weight. Um and she's really active now. Really, really enjoying life. (SS)*

*Where we have had people who have come to the service, initially on three to one support. High levels of anti-psychotic medication who are now on one to one support, holding down jobs, hardly any medication. That is a positive outcome for that. (SM)*

Some described how medication withdrawal has helped people to move from institutions to more independent living in community settings.

*...when the doctor had reduced... it took a longer period but at the end it was successful. ...that man's support has moved from like seven hospitals and he is now in his own flat and he's doing amazing, he is doing really well. (SM)*

### **The Need for a Cautious Medication Withdrawal**

Participants emphasized the importance of withdrawing medication gradually over time.

*But risperidone is the one that they gradually reduced and we haven't seen any side effect on it so she's on 250 microgram in the morning and night so it's going down, down, down until we get to a point where we stop. It doesn't have an effect on her so she's okay. (SS)*

### **Success Stories of Medication Withdrawal**

Staff described stories of people who moved from an institution to community homes with a lot of medications but now are on a minimum medication.

*...he came with, um, warnings from where he was before. They had a lot of issues, he'd been to a lot of different places. He'd had a very troubled life, ...came with a lot of medications. He is now only on one medication and that is just PRN. He has only needed one tablet from his, um, since he moved in . . . . (SM)*

### **Medication Withdrawal Symptoms**

Participants then had a long discussion about the withdrawal symptoms they have noticed in people they support, particularly affecting their quality of life.

*Some medication they've reduced, it doesn't have effect on them and you can't tell the difference. And some of them you can tell the difference because they start becoming challenging, agitated, restless, and kind of like, isolate themselves. And then their quality of life, kind of like changed, in terms of not eating, their wellbeing, like not going out in the community and things like that. (SS)*

Participants discussed the various causes of withdrawal symptoms. One service manager highlighted that deterioration in behavior upon withdrawal of medication is not always related to the withdrawal itself but could be due to other factors that affect a person's life.

... . . . they started reducing the dosage. He then had an instance where he actually set fire to his home but when we were looking at that, that was actually to do with other factors and things, that he wasn't happy in his home. He was trying to voice this to his community team and the local authority. Um, he didn't like his neighbours and there was an incident with the neighbour and then it resulted in him setting fire to his home. But actually it was all the external factors really. (SM)

### **Strategies to Help with the Withdrawal Symptoms**

This was followed by a discussion about how to help with withdrawal. Suggestions included

#### **Availability of Information on Medication Withdrawal**

(a) the availability of more information on the issue,

*I guess what would help is if there is more information available for the staff to help them, help them to cope with the behaviours when someone is withdrawing from the medication. (SM)*

#### **Working Together and Shared Decision Making**

(b) all relevant stakeholders working together, including the person with intellectual disabilities, their families, support staff, and the multidisciplinary team,

*So, I can see that, you know, working together with everyone, the staff, the family, it might not be only the medication being given but maybe alternative medication can also be given to help them, while the medication is being withdrawn. (SM)*

#### **Training Families on Medication Withdrawal Issues**

(c) training families about the issues around withdrawal, and

*“Educating families and one of the things we try” (SM)*

#### **Incorporating More Information on Medication Withdrawal Within the Existing Staff Training Programme**

(d) including more information on withdrawal issues within the current training programs.

*We spend quite a bit of time, in our meds trainer's management, quite a bit of time talking about effects and side effects of certain medications. But not necessarily enough on withdrawal. (TR)*

*I think it is doable. I think we have to make that time and, you know, you invest that time, you see the results. (SS)*

## Discussion

Although all participants expressed concern about overmedication, the opinion was split regarding the justification of medication use. However, all agreed that a balanced approach is needed to weigh up the benefits of the medication against its side effects. Some even expressed concern that because of the NHS England STOMP initiative (Branford et al., 2019), some prescribers may be reluctant to prescribe psychotropics for what staff thought was a psychiatric disorder.

There are published studies from Australia and the Netherlands on staff perception of medication use for CB. In a questionnaire survey of 194 care staff from 14 residential settings in the Netherlands, G. de Kuijper and van der Putten (2017) found that most had unrealistic expectations regarding the positive effects of antipsychotics on the cognitive and behavioral functioning of people with intellectual disabilities. Similarly, Donley and colleagues (2012), in their interviews with eight care staff in Australia, reported that many staff regarded medication as the best and only solution for CB. However, most interviewees claimed that an effective alternative to medication was talking to the client, and they needed more specific information regarding the side effects of psychotropic medication and its alternatives. After conducting four focus groups from three organizations in the Netherlands, Kleijwegt and colleagues (Kleijwegt et al., 2019) concluded that a large majority of support staff perceived antipsychotics to be effective in controlling CB.

There are some similarities and differences between the studies from Australia and the Netherlands and our findings. The views about the utility of psychotropics in treating CB were divided in our study. For example, some support staff but not the service managers and trainers in our study felt that medication has a role to play. This chimes with the views of staff who participated in previous studies in Australia and the Netherlands. On the other hand, in our study, some support staff but not the managers and trainers described the use of medication as a “chemical restraint” and also suggested that sometimes medication, particularly when used as a PRN (as required), could be abused as they are used to sedate people rather than to help them with their distress. However, almost all participants (including support staff, managers and trainers) in our study agreed that alternatives to medication such as psychosocial and behavioral interventions should always be explored first to address CB.

There could be several reasons for the discrepancy between the findings of our study and the previous studies from Australia and the Netherlands. First, some of these studies are old, so they have failed to capture the recent change in staff views. There are cultural differences among these countries. In the UK, services for people with intellectual disabilities are specialized and relatively well developed compared with the rest of the world, helping to improve staff views on medication use. In the UK, the NHS England initiative, STOMP, may be helping to improve staff views (Branford et al., 2019). Also, participants in our study came from large service provider organizations with better training on PBS and STOMP initiatives and an emphasis on psychosocial intervention. However, it seems that although the service managers are more advanced in their views, some support staff themselves need further training to change their attitude toward the use of medication for CB. Also, the staff from smaller organizations (providing community service for less than 100 people in less than two dozen community homes within a particular region of the UK) are unlikely to have similar support for implementing psychosocial interventions as the larger organizations (providing community service for over 1000 people with intellectual disabilities in more than 100 community homes throughout the UK), therefore, highlighting the need for a training program like SPECTROM.

Many participants in our study expressed concern about the side effects of medication and drug-drug interaction from polypharmacy leading to poor QoL of the person with intellectual disabilities. Some staff even provided examples of improved QoL among people they support who became more animated when their medication was withdrawn after many years of use. This is supported by studies from the Netherlands and the USA (Deb, Limbu, et al., 2022; Ramerman et al., 2018). Most staff from large organizations in the UK are familiar with the PBS principles, and many have a PBS support team, although that resource is not always adequate. The smaller organizations are unlikely to have such a specialized PBS support team. In any case, most staff felt the need for more support from their organizations and managers to help rationalize medication use, particularly when medication withdrawal makes behavior worse. To address this critical issue of staff support, in SPECTROM, we have provided a list of recommendations for the service managers and organizations to provide adequate support for the support staff themselves.

As for the withdrawal of medication, participants described both success stories and failures. There was a general anxiety among the staff about the withdrawal as most felt that this might fail if not done correctly. In a recent questionnaire survey the PBS practitioners in Australia reported carers' (both paid and family carers) attitude as one of the barriers for reducing restrictive practices (Leif et al., 2023) thus highlighting the urgent need for carer training in this area. In Kleijwegt and colleagues' study (Kleijwegt et al., 2019), staff felt the lack of staff time is responsible for the failure of many attempts of medication withdrawal as there are not enough resources to address any



potential deterioration in behavior following the withdrawal. Staff felt that there should be a personalized withdrawal and contingency plan. Staff in the current study expressed a similar opinion. A relevant issue was the withdrawal side effects and particularly how these could manifest as CB. There seems to be a general lack of awareness among staff about this issue which may lead to the reinstatement of psychotropics after withdrawal if there is an emergence of CB. To address this issue, SPECTROM devotes a large section to withdrawal side effects.

There was a universal acknowledgment of the lack of staff knowledge on psychotropic medications, particularly their side effects. This has been highlighted in many previous studies of staff surveys (Christian et al., 1999; Donley et al., 2011; Kleijwegt et al., 2019; Lalor & Poulson, 2013; Erickson et al., 2016; Fretwell & Felce, 2007; Leif et al., 2023), including our own study (G. L. Unwin, 2014). G. de Kuyper and van der Putten (2017) found that of the 194 participants in their questionnaire survey, 94% scored below the cutoff for knowledge of medication, and 60% indicated they needed education and training on the subject. After interviewing 22 key care staff and three house managers, Fretwell and Felce (2007) concluded that staff knowledge of the potential side effects of antipsychotics was limited. The majority of participants identified only two side effects, and most of them felt insufficiently informed and needed further training. Apart from a significant lack of training, Lalor and Poulson (2013) also explored in an interview with eight care staff the issues around the medication's negative impact on people's QoL, the ethical implications of using medication (for example, prescribing in the absence of informed consent), and the relationship perceived by care staff with the organization management. Although most staff in large organizations receive some training on medication and STOMP-related issues, this was not comprehensive enough for the staff in our study. There was a unanimous call for more information on medications and their side effects. In smaller organizations, staff are unlikely to receive even basic training on medication and STOMP. This is why we think SPECTROM should be helpful for both large and small service provider organizations, as the training provides comprehensive information on psychotropic medications and their side effects. Staff in our study also mentioned that all stakeholders, including family caregivers, should receive STOMP training.

More importantly, the findings of this study helped to inform the development of SPECTROM resources. For example, SPECTROM has a whole module on physical disorders and also a separate module on the assessment of CB to address staff concerns about the physical causes of CB, requiring a comprehensive assessment of all causes for CB. We also developed a Comprehensive Assessment of Triggers for Behaviors of Concern Scale (CATS) (Limbu et al., 2021) to help staff detect triggers for CB to help with the functional analysis of behavior (Matson et al., 2012). Staff concern

regarding the lack of appropriate medication review is addressed in SPECTROM through the development of a checklist for the staff team to go through in preparation for a formal medication review by the prescriber. SPECTROM also provides a list of questions that the staff should ask the prescribers during the formal medicine review in the clinic. Staff concern about the side effects was addressed by including resources like freely downloadable accessible psychotropic medication leaflets from the internet. SPECTROM has devoted a whole module on medication withdrawal to address staff anxieties about medication withdrawal.

Some staff raised the crucial issue of shared decision-making, saying nobody asks the person with intellectual disabilities what they want. This problem has been mentioned in previous surveys of people with intellectual disabilities, and their family caregivers (Hall & Deb, 2008; Hassiotis et al., 2016) and similar views were expressed by other stakeholders and family caregivers (Deb & Limbu, 2022). Through SPECTROM, we hope to encourage shared decision-making, particularly with the involvement of the person with intellectual disabilities and their families from the outset. We have developed three modules in relation to this: “effective liaison with families” (Deb & Limbu, 2022), “effective engagement with the person with intellectual disabilities,” and “communication issues.” We believe that all of these should help with shared decision-making. Moreover, the accessible medication leaflets and the Yellow patient-held passports should also help with shared decision-making.

### ***Strengths of the Study***

Previous studies of staff surveys primarily concentrated on staff knowledge of psychotropic medication. In the current study, for the first time, we focused on the staff attitude and perception of using psychotropics to address CB. One strength of this study is that it not only examined support staff’s opinions but also examined service managers’ and trainers’ opinions. Previous studies have focused primarily on the experiences and perceptions of support staff and family caregivers. Ours is the first study that examined support staff, service managers and trainers’ perceptions of using psychotropic medication for CB. Another strength of this study is that support staff, service managers, and trainers were interviewed separately to avoid the influence of service managers on support staff’s responses. Another strength of our study is that the participants came from several different service provider organizations, reflecting different experiences, thus potentially making the findings more generalizable. Also, the anonymized data analysis allowed support staff to express their opinion freely, thus increasing the face validity of our findings. In SPECTROM, we have an extensive section on the side effects of psychotropic medication, as staff always wanted more information on the subject. SPECTROM also has accessible information leaflets on 32 commonly used psychotropics in people with intellectual

disabilities. These could be downloaded free of charge from the SPECTROM webpage (<https://spectrom.wixsite.com/project>). All these leaflets describe both common and rare but serious side effects of these medications. Independent analysis of interview data by two authors helped with the consensus.

### **Limitations of the study**

The study's primary limitation is the small number of participants involved. However, more than eight participants in a focus group would have hampered the free and equal expression of everyone's views. This could have been rectified by interviewing several staff individually or using mixed methods, including a questionnaire survey to supplement data from the focus groups. The other option was to increase the number of focus groups. Another problem with generalizing the findings from this study is that all participants were recruited from large service provider organizations. Therefore, the views and experiences of staff working in smaller organizations were not captured, which could be different. Another weakness is that service managers identified the support staff for the focus groups, so managers may have chosen support staff eager to get their voices heard on this topic.

### **Conclusion**

Our exploration of the views of support staff, service managers, and trainers on using medication to manage CB in people with intellectual disabilities revealed conflicting views. Some support staff but not the managers and trainers felt medication is justified if it provides good quality of life for the person. On the other hand, some support staff, not the managers and the trainers felt that medication is a form of chemical restraint. In general, house managers and PBS trainers were critical of using medication for CB. However, all support staff and managers agreed on a holistic approach to managing CB. There was universal anxiety about withdrawing medication, although many staff presented stories of successful withdrawal in persons they support leading to improved quality of life due to reduced medication side effects. Others shared stories of unsuccessful withdrawal leading to side effects affecting the person's quality of life. All agreed on the need for more information on medications, their indications and side effects.

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## Author contributions

SD is the grant holder. All authors were involved in the conception and design of the study. SD and BL conducted the focus groups. BL analyzed focus group data, and SD acted as the second-rater. TW and GU advised on the qualitative research design. All authors contributed substantially to the preparation of the manuscript and approved the final version of the manuscript.

## Data availability statement

Transcripts of the focus group discussions are available from the authors subject to approval from the study sponsors and the funders.

## Institutional Review Board Statement

This study did not require ethics approval as no new or patient-related data were collected. Also, the participant's views were analyzed anonymously, and no personal data were collected from the participants.

## Informed Consent Statement

Written informed consent was collected from the participants before the start of the focus groups.

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